A Personal Journey in Taiwan’s Hospice Palliative Care Movement

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Abstract

Hospice palliative care started in Taiwan in 1990. Foundations of Christian, Catholic and Buddhist background and associations with medical, nursing and various social backgrounds joined in promotion of this modern humanistic medical care. Government organizations, especially the Ministry of Health and Welfare and the National Health Insurance (NHI) added policy momentum. Total subsidies for hospice care were provided by NHI. Hospice Palliative Care Act (a Natural Death Act) was enacted in 2000 and Patient Self-Determination Act passed in 2016. Clinical Buddhist Chaplaincy training program was started in 1998 and exported to Japan in 2013. A Taiwan Coma Scale was proposed for shortening of terminal suffering.

Keywords: Hospice Care; Palliative Care; Hospice Palliative Care Act; Patient Self-Determination Act; Clinical Buddhist Chaplaincy; Taiwan Coma Scale; National Health Insurance; Good Life; Good Death

Full Paper

In 1967 Dr. Dame Cicely Saunders founded the St. Christopher’s Hospice in London, introducing active medical treatment and care to relieve physical, psychological and spiritual suffering, and offering palliative care during the last phase of patients’ lives [1]. This humane form of holistic healthcare has gradually spread around the world, reaching Taiwan in 1990. The first hospice ward was established by Dr. David CH Chung in the Christian Mackay Memorial Hospital in Taipei County in 1990 [2-5]. Hospice home care was started by Ms. Co-Shi Chao in 1990 [6]. The second hospice ward was established in 1994 at the Catholic Cardinal Tien Hospital in Taipei County. In 1994 the author was invited by the Christian Hospice Foundation of Taiwan to visit a few leading hospices in Japan to learn more about the management [2]. In 1995 the author opened a palliative ward at the National Taiwan University Hospital in Taipei City. In 1995 Buddhist Tzu Chi Hospital in Hualien (eastern Taiwan) opened a hospice ward. Thus hospice services gradually spread around Taiwan.

Foundations and Societies

In 1990 a Christian Hospice Foundation of Taiwan was established [7]. In 1993 Catholic Sanipax Socio-Medical Service & Education Foundation (Kung Tai) was found [8]. In 1994 the author started the Buddhist Lotus Hospice Care Foundation (Lotus Foundation) [9]. The cooperation of these 3 religious organizations became the major momentum of Taiwan's hospice movement.

Taiwan Hospice Organization was born in 1995 [10]. The author became its second president from 1999 till 2003. Taiwan Motor Neuron Disease Association joined in the hospice movement in 1997 [11]. In 1999 Taiwan Academy of Hospice Medicine was organized by physicians interested in hospice care [12]. Then Taiwan Association of Hospice Palliative Nursing in 2005 [13]. In 2007, Taiwan Association of Clinical Buddhist Studies was organized by persons participated in promotion of clinical Buddhist chaplaincy [14].

Governmental support and impact on policy [15]

In 1995, the Department of Health (DOH) (later promoted as Ministry of Health and Welfare, MOHW) organized a taskforce to develop hospice palliative care. In 1996, the DOH declared that providing palliative care, including do-no-resuscitation (DNR), in terminal care is appropriate and legally justified.

In 1996, the National Health Insurance (NHI) started to include the hospice home care in the funding program. Since 2000, NHI subsidized hospice in-patient care, with per capita and per diem program.

In May 2003, “Cancer Control Act” was promulgated. In this law, “Availability of hospice service for terminal cancer patients” is listed as one of the 5 major tasks of cancer control.

In 2004, the DOH started a pilot study in providing hospice combined care to let the terminal patients to be cared by his/her original physician and hospice team together at the original ward service.

In 2005, the DOH published the “National Cancer Control Project 2005-2009”. In the project, the provision of quality hospice palliative care is included as a part of the integrated cancer control and care. The aim was to increase the palliative care coverage rate to 50% of cancer death. Since 2015, hospice combined care was subsidized. Gradually, hospice palliative care was also encouraged and required by the Taiwan Joint Commission on Hospital Accreditation when

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the author was surveyor and consultant to it.

Besides terminal cancer patients, in 2009, the NHI started to pay for hospice care for terminal patients suffering from all major organ failures (such as brain, heart, lung, liver or kidney failures). Patients suffering from amyotrophic lateral sclerosis and AIDS were also covered.

Legal Supports in Hospice Care

In 2000, Taiwan's Natural Death Act was passed with the name "Hospice Palliative Care Act" [16,17]. In Article 1, "The Hospice Palliative Care Act is specifically stipulated to respect terminal illness patients' will on the medical treatment, and protect their right." In Article 4, "Terminal illness patients may write a letter of intent for the choice of Hospice Palliative Care (HPC) or Life Sustaining Treatment (LST). In Article 5, "A person with age of twenty years or above and have the legal capacity may prewrite such letter of intent referred in article 4." Thus our people have the legal right to withhold cardiopulmonary resuscitation (CPR), i.e. to choose DNR and the right to withdraw futile CPR, such as withdrawal of mechanical ventilator. In Article 6-1, "With the consent expressed in the letter of intent by decision maker or the medical surrogate agent as set forth in the article 4 paragraph 1 or article 5, the central competent authority (DOH/MOHW) shall note this will in the National Health Insurance certificate (hereinafter "NHI card"). The NHI card is routinely used by every patient in asking for medical care or consultation in any clinic or hospital. The author had the privilege of having his NHI card as the first one to include this DNR intent.

In January 2016, "Patient Self-Determination Act" was enacted, to be effective 3 years later [18]. In Article 3 of this Act, the Life Sustaining Treatment (LST) is defined as the following measures: Any medical and nursing measures which can prolong the life such as cardiopulmonary resuscitation (CPR), artificial ventilation, mechanical life sustaining system (such as ECMO), blood substitutes, special treatment for specific diseases, for example, chemotherapy, dialysis, antibiotics for fatal infections, artificial nutrition and artificial liquid feeding, etc. In Article 13, the patient can ask for withholding or withdrawal of whole or part of the life sustaining treatments if he/she is 1. A terminal patient, 2. In irreversible comatos state, 3. In persistent vegetative state, 4. In severe dementic state, 5. Patient is in intolerable pain, incurable disease without adequate solution under the current medical standard. The above items must be confirmed by 2 specialists and Item 5 must be confirmed by consultation with hospice team [19].

In promotion of the concept of hospice care the author tried to educate the public, "Filial duty and love should find its expression in being with the family member at the end of his/her life, and in encouraging acceptance of disease, quiet life in his last days and peaceful passing"[3]. And to educate the physicians, "Where it is unavoidable, the death of a patient is not a medical failure. Not being able to facilitate a peaceful and dignified demise is, however" [3].

Clinical Chaplaincy in Hospice Care

In the Catholic and Christian tradition, many chaplains received some medical or nursing training before they started their pastoral role. These chaplains are competent in participating in hospice care. However, there was no such tradition in the Buddhist history. In Taiwan, about 70% populations are Buddhist or Taoist believers. In 1998, The Lotus Foundation started a Clinical Buddhist Chaplaincy (CBC) training program at the Palliative Unit of National Taiwan University Hospital. This include a 70-hour classroom courses and 80-hour bedside practice[20]. Up to the present we have 129 nuns or monks participated in training, 86 finished bedside training, 56 completed the course (including 3 Catholic nuns). At present, 34 CBCs were serving in 41 hospices. They are successfully participating as active team member of hospice ward care, combined care and home care. Since 2013, this CBC program was exported to Japan through Japan's Zenseiky Organization [21-22].

Taiwan Coma Scale [23]

Coma or unconsciousness is the result of insult to the brain. It is qualitatively described as mild, medium or deep coma. The Glasgow coma scale (GCS) proposed by Teasdale and Jennet was widely used in Taiwan for making quantitative measure of coma. However, the GCS made the lowest scale to 1 for those “none” responses in eye , speech and limb movement . The total lowest scale is 3. The family in Taiwan usually felt that there might be some hope for the scale of 3, and continued to wait for miracle to occur. It costed the patient to suffer from the continual torture of the futile medicine. Chen suggested to establish a Taiwan Coma Scale [23] which would make the lowest point of the "none" response to 0 for each category. When the scale reaches 0, it might be easier to persuade the family members for discussion about withdrawal of the futile life sustaining treatment. Hope this will further improve the quality of hospice care in Taiwan.

Taiwan’s Current Status of Hospice Palliative Care

Up to present, Taiwan has 57 hospice wards for the population of 23 millions. 93 hospitals provide hospice home care, 141 hospitals providing hospice combined care, and 155 hospitals providing community hospice care, covering almost all cities and counties. The author is participating in planning of construction of a Buddhist Taichung Chengte Hospice, a 90-bed hospital built for hospice care in the central part of Taiwan [24]. Hope this first independent hospice (not as part of a general hospital) in Taiwan will become a St. Christopher's Hospice of Asia, with special emphasis on Buddhist local style hospice care and training center of Clinical Buddhist Chaplaincy.

Although we are not satisfied with our result, the international survey of the quality of death and also quality of palliative care by the Lien Foundation ranked Taiwan as the 14th/40 in the world in 2010 and 6th/80 in 2015. Taiwan ranked the first in Asian Countries in both times [25-26]. We will continue to improve our quality of care and coverage of hospice care in Taiwan.

In joining our colleagues in promotion of hospice palliative care, the author was honored to receive a Global Love of Lives Award of Chou Ta Kuan Foundation in 2010 as Terminal Care Anchor [27]. In 2016, the Health, Welfare & Environmental Foundation of the
Legislative Yuan (Taiwan's Senate) and the Ministry of Health & Welfare gave the author a Medical Service and Dedication Award to express appreciation to the entire hospice care teams' contribution to Taiwan's holistic medical care [28].

Finally, the author wishes to express his deep thanks to his family members, teachers, classmates, friends, colleagues for their continual nurture, teaching, guidance, support and help throughout his life, with special thanks to all members in the hospice care promotion teams and all the patients and their families who accepted the care. Life is the best gift and good death is the most beautiful blessing [29].

May all the sentient beings of the world have a good life and peaceful departure of this life and smooth travel to a new life in the heavenly kingdom of God or pure land paradise of Amitabuddha.

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